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ABSTRACT

This document consists of the first section of a book written to educate and inform those in the helping professions on how to deal with Acquired Immune Deficiency Syndrome (AIDS). The two chapters in this first section present an overview of the AIDS crisis and provide a foundation for the rest of the book. "Emerging Trends: AIDS Today and in the Future" (Craig D. Kain) surveys the sociological and psychological development of the AIDS crisis in the 1980s and sets the stage for future developments of the crisis in the 1990s. It reviews the significant medical, political, social, educational, and psychological events of the AIDS crisis, relying on the concept of emergent trends to tie together the events of the first 10 years of the epidemic. In exploring future trends, 10 areas of importance to counselors are identified. "A Research Update for Counselors" (Joseph R. Guydish and Maria Ekstrand) provides an in-depth review of psychosocial research on human immunodeficiency virus (HIV) spectrum disease. The chapter is clinically focused and surveys literature on HIV epidemiology, persons at risk for AIDS, asymptomatic seropositive persons, and people diagnosed with AIDS or AIDS-Related Complex. The central theme of the chapter is prevention, described as the greatest hope counselors have for slowing the continual spread of AIDS. Both chapters describe AIDS work in its broadest scope and emphasize the major thrust of the guide--that counselors must become involved. (NB)

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Section One

OVERVIEW

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TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)"

Section Introduction

Before beginning or continuing on a journey, a person often finds it necessary to pause and take account of where he or she has arrived and where he or she intends to go. Counselors who have been deeply involved with AIDS work, and those who merely anticipate becoming involved, need to assess the current scope of the AIDS crisis. Thus, *No Longer Immune: A Counselor's Guide to AIDS* begins with an overview section that reviews the first years of the AIDS epidemic and anticipates the prominent issues that counselors will face in the coming years.

In the book's opening chapter, Kain reviews the significant medical, political, social, educational, and psychological events of the AIDS crisis. He relies on the concept of emergent trends to tie together the events of the first 10 years of the epidemic. Kain then turns to the decade of the 90s and suggests 10 areas of importance to counselors. These future trends set the tone for the rest of the book; many are examined in their own individual chapters in the book's other sections.

In chapter 2 Guydish and Ekstrand provide an in-depth review of psychosocial research on HIV spectrum disease. This chapter is clinically focused and surveys literature on HIV epidemiology, persons at risk for AIDS, asymptomatic seropositive persons, and people diagnosed with AIDS or ARC. The central theme of this chapter, as in many of the other chapters to follow, is prevention, which continues to be the greatest hope counselors have for slowing the continual spread of AIDS.

Both chapters describe AIDS work in its broadest scope. Together, these chapters emphasize the major thrust of *No Longer Immune: A Counselor's Guide to AIDS*: counselors must become involved.

Chapter 1

EMERGING TRENDS: AIDS TODAY AND IN THE FUTURE

Craig D. Kain

It is hard to believe that nearly 10 years have passed since the first immune-suppressed man asked for help. For tens of thousands of men, women, and children touched and torn by acquired immune deficiency syndrome (AIDS), the 80s was a decade where the passage of days, years, and lives was seen with crystalline clarity. There existed a heightened awareness of living on what Monette (1988) described as "borrowed time." Many things have changed in those 10 years; many things have not.

In its broadest sense, this chapter reviews the history of AIDS. To work effectively counselors must have a historical and societal context in which to place their clients and themselves. Examining the course of AIDS in the 80s reveals a number of trends. Five categories, though hardly distinct, emerge, offering a framework from which to examine these trends. The AIDS epidemic has affected science and medicine, politics, society, education, and counseling. Although these affected areas show considerable overlap, they will be discussed as separate entities in the course of this chapter.

Looking at the past is necessary, yet hardly sufficient. Counselors know that to get stuck in the past is to lose sight of the future; with AIDS the future is where hope lies. The second part of this chapter looks ahead, attempting to foreshadow crucial developments in the AIDS crisis and the impact they may have on counselors and other human development specialists.

Although examining the past and forecasting the future are the stated goals of this chapter, another subtler purpose

exists. In the 1990s many new therapists and counselors will have to confront AIDS issues in their work. It will be important for them to have a strong background and understanding of what constitutes "the specter of AIDS" (Simon, 1988). Counselors who have had little experience with AIDS work will find that this chapter provides them with an introduction and explanation of terms, concepts, and issues. Counselors familiar with AIDS will find that this chapter offers them a concise overview and a challenging preview of the future.

AIDS In the Eighties

An Emergent Trend in Science and Medicine: The Language of AIDS

AIDS caught the medical profession off guard, coming at a time when epidemiologists believed that infectious disease no longer posed a threat to the developed world. Noninfectious conditions such as cancer, heart disease, and degenerative diseases were thought to pose the remaining menace to the public health (Gallo & Montagnier, 1988). AIDS changed these assumptions, creating a major medical catastrophe (Altman, 1986).

At the end of the 80s there was no cure, no antidote, and no vaccine for AIDS. The decade's "major" advances, the discovery of the virus believed to cause AIDS and the use of AZT and other experimental drugs to prolong the life of people with AIDS, pale in comparison to the increased severity of the epidemic. Even Gallo and Montagnier, the investigators responsible for establishing the cause of AIDS, remarked that "in some respects, the virus has outpaced science" (1988, p.41).

What, then, have medical and scientific researchers contributed to the fight against AIDS? Their largest contribution lies in the lexicon of words and phrases that has emerged as a way of describing, characterizing, and communicating AIDS. Language, though often taken for granted, provides a tool for conceptualizing the unknown. In this ability to construct the world, language is most powerful. Words given to the epidemic from the very start have helped to shape, sometimes in deleterious ways, the course of the crisis we call AIDS.

The language of AIDS began with a small, almost unnoticeable report in the July 4, 1981, issue of the Center for

Disease Control's *Morbidity and Mortality Weekly Review*. The report outlined common symptoms of patients in New York City and California suffering from **Kaposi's sarcoma** and **pneumocystis pneumonia.** Until that time these terms were rarely used, referring to diseases that were seldom seen by doctors and certainly not in a fatal configuration. Kaposi's sarcoma, purplish lesions or patches appearing on the skin and affecting other organs like the lungs, heart and, most often, the lymph nodes, was known long before AIDS existed; it was an exceptional disease found in older subjects of Mediterranean descent and was usually "tranquil" (Leibowitch, 1985). Similarly, pneumocystis, a pneumonia caused by microorganisms, was, prior to AIDS, rarely seen (Osborn, 1987). The Center for Disease Control's (CDC) report marked Kaposi's sarcoma (**KS**) and pneumocystis (**PCP**) as entries into the language of AIDS.

As the number of cases of Kaposi's sarcoma and pneumocystis increased, a new term was added to the AIDS dictionary, with detrimental consequences. In the year following the first report by the CDC, the Center began referring to "homosexual or bisexual men" when speaking about the illnesses. It would have been far more appropriate for the CDC to speak of particular *behavior* as opposed to *identity*, and its failure to do so set the tone for the first name for what is currently known as AIDS: **GRID—gay-related immune deficiency.**

Although the term GRID was not specifically used by the CDC, it, or variations on the theme (i.e., "gay plague") soon came into common use. This emphasis on the gay aspects of the disease affected early research on AIDS; instead of focusing on a specific organism responsible for GRID, researchers looked for factors in the "gay life style" to explain what was going on (Altman, 1986). Even today, public perception of the disease and its sufferers continues to be affected by the term GRID's reference to sexual orientation.

The term GRID gave way to its logical heir, **AIDS**, **acquired immune deficiency syndrome**, a term used to describe a virtual smorgasbord of illnesses including KS and PCP as well as **toxoplasmosis**, **thrush**, and **cytomegalovirus**. The term AIDS quickly spawned a related term, **ARC—AIDS-related complex**. Doctors used this acronym to describe patients who demonstrated many debilitating symptoms like fever and sweats, general persistent fatigue, and persistent diarrhea and swollen glands, but failed to qualify for an AIDS diagnosis under the CDC's

guidelines, which demanded the appearance of an "**opportunistic disease.**" This high-gloss term euphemistically referred to a host of disfiguring and destructive diseases that prey on weakened immune systems.

As medical research progressed, attention turned from genetic hypotheses for AIDS, linked to some innate homosexual predisposition, and from life-style hypotheses, linked to particular locations frequented only by gay men (Altman, 1986), to a viral cause for AIDS. This viral hypothesis, currently in popular acceptance, added three more terms to the dictionary of AIDS. Due to the particular political nature of the discovery of the AIDS virus, three separate names were used to designate what is and was the same virus. The American research team claimed the virus was **HTLV-III**, a distant relative of the HTLV (human T-lymphotropic virus), discovered by the National Institute of Health's Gallo. The French named their version of the virus **LAV** (lymphadenopathy associated virus), declaring their discovery a year before that of Gallo's was announced. Finally, an international commission changed the name to **HIV**, **human immunodeficiency virus**, eliminating the confusion caused by two names for the same entity (Gallo & Montagnier, 1988).

Although the research and consequent isolation of the HIV offered no immediate solutions to the crisis of AIDS, they did force new words into the vocabulary of the layperson. It was clear that the HIV virus was a **retrovirus**, a virus coded in the RNA of a cell as opposed to the DNA of a cell. The virus targeted the specialized **T-4 lymphocyte** cells, the cells responsible for the proper functioning of the body's immune system, and annihilated them.

Soon after the discovery of the AIDS agent, a laboratory test was developed to detect antibodies to HIV in the blood. This test, the **enzyme-linked immunosorbent assay (ELISA)** test, was created for the country's blood banks in an effort to keep the nation's blood supply free from AIDS. This, however, was not the only way the test came to be used. Individuals began relying on the test to assess their exposure to AIDS. Getting "**tested**" took on new meaning in the sociopolitical culture of the 80s. This popular use of the ELISA test resulted in new connotations for the terms "**seronegative**" and "**seropositive.**" These terms, used to describe the lack of antibodies, or the presence of such antibodies, now implied life and impending death.

Although a positive result to the antibody test meant a person had been exposed to the virus, it did not mean a person had AIDS. Being **asymptomatic**, without overt warning signs, implied possible infectiousness, although at a rate thought to be less than that of symptomatic individuals (Heyward & Curran, 1988).

As the medical knowledge of AIDS increased, so too did the use of new terms describing the new situations that arose. Doctors as well as politicians, public health officials, counselors, reporters, and the public at large began to talk of **"risk groups," "the worried well,"** the **"exchange of bodily fluids,"** and **"safer sex."** AIDS patients were renamed **PWAs**, **people with AIDS**, in an effort to remove the notion of victimization.

To combat the ravaging illness that affected the men, women, and children with AIDS, medical researchers began pulling existing drugs off their shelves, trying anything reasonably likely to help those infected. Each drug added an additional entry into the growing AIDS dictionary. Although **AZT**, (**zidovudine**), the first effective anti-AIDS agent, brought hope that AIDS would not remain incurable forever (Gallo & Montagnier, 1988), its toxic side effects made it less than perfect, and certainly not the final answer (Yarchoan, Hiroaki, & Broder, 1988). By its direct antiviral action and by its partial restoration of immune functions, AZT may have a great effect if given early in the course of HIV infection, possibly preventing the progress of AIDS in some individuals (Yarchoan et al.). In addition to AZT, **CD4** seems to be a promising agent, serving as a viral receptor binding to the HIV, thus preventing it from infecting new cells (Gallo & Montagnier). **Aerosal pendamidine** and **dextran sulfate** also appear on the list of promising drugs. Additions to this list will be tempered by the fact that HIV appropriates the biosynthetic apparatus of the host cell. This means that drugs effective against the HIV tend to damage the host. Any vaccine must also take into consideration the HIV's capacity to integrate into the chromosomes of the host cell.

Implications for counseling. Counselors will need to keep familiar with current discoveries in the field of medicine and science. For many, this will be like learning a foreign language, with new diseases and new drugs added daily to their vocabulary. Clients with AIDS or at risk for AIDS are inundated with these terms and often use them as a way of describing their physical and *psychological* state. If counselors are to understand their clients, they must understand their clients' language.

An Emergent Trend in Politics: Resistance

Since first recognized, AIDS has been not solely a medical crisis but a political crisis as well. AIDS affects stigmatized segments of society, making the politicization of the syndrome more serious. Prejudice confounds and clouds politics, making the politicization more tragic. Emerging from the tangled web of political pomp and circumstance is the trend toward resistance.

Resistance takes on many shades and meanings. Resistance is an influence that hinders progress, as counselors working with highly resistant clients are aware. Another meaning of resistance refers to an organization or movement opposing the authorities. Both uses of the word fit the AIDS crisis. In the political arena, many people have hindered and opposed progress. In sharp contrast, the people most affected by AIDS have undertaken the formation of resistance movements, working for positive change.

AIDS is, in its purest sense, a bipartisan issue affecting Republican and Democrat alike, infecting liberals and conservatives without discrimination. However, to ignore the fact that the onset of AIDS occurred in the first year of the Reagan administration would be an oversight. The Reagan administration responded to the AIDS epidemic with great resistance, attesting to the notion that the politicization of AIDS reflects the circumstances of American politics in the 80s (Altman, 1986).

To look at AIDS and the government is to look at the availability of money for research, money for education, and money for prevention. Although the AIDS epidemic quickly fostered a volunteer response, particularly in gay communities hardest hit, which exemplified the kind of communal grassroots organizing Reaganism extolled, the Reagan presidency was committed to trimming the financial fat off the country's budget, resulting in considerable cutbacks in funds available for both medical care and research (Altman, 1986).

In March of 1983, the Public Health Service issued the first risk-reduction guidelines in the federal government. "Sexual contact should be avoided with persons known or suspected to have AIDS" and "Members of high-risk groups should be aware that multiple sexual partners increase the probability of developing AIDS" represented the sum total of the U.S. government's attempt to prevent the spread of acquired immune

deficiency syndrome almost 20 months after the original alert to AIDS (Shilts, 1988).

The outpouring of attention to the handful of heterosexual cases in early 1985 proved crucial in changing the lagging pace of the government's response to AIDS (Shilts, 1988). The widespread talk of heterosexual transmission of AIDS seized government officials, lending support to the notion that viewing AIDS as a "gay disease" was, until then, at least in part, responsible for the tepid response of the government.

Although funds became increasingly available as the number of heterosexual AIDS cases grew, the Reagan administration's resistance to a wholehearted commitment to prevent AIDS still showed. In 1985, Reagan asked the U.S. Surgeon General, C. Everett Koop, a recognized conservative, for a report on AIDS. Koop's report sat on the president's desk for 18 months before Reagan finally addressed it at the Third International AIDS Conference (Schram, 1988).

Later, in 1987, the president created his own commission on AIDS, which, after many politically motivated reorganizations, was finally chaired by Admiral James D. Watkins. The commission reported that "as long as discrimination occurs and no strong national policy with rapid and effective remedies against discrimination is established, individuals who are infected with HIV will be reluctant to come forward for testing, counseling and care" (Schram, 1988). The commission recommended that the president issue an executive order banning discrimination on the basis of considering HIV infection as a handicapping condition; the president responded by ordering yet another study, this one on discrimination (Schram).

The Congress too, became embroiled in political battles over AIDS. AIDS legislation, passed toward the end of Congress's 100th session, was the *first* comprehensive federal response to the AIDS epidemic since it was identified at the beginning of the 80s (Molotsky, 1988). The one billion dollar plan established prevention programs, developed care and treatment networks, and accelerated research efforts to find vaccines and cures. It did not, however, ensure confidentiality for patients whose tests showed they were carrying the disease, nor did it provide comprehensive education and mental health components. As it stood, the "AIDS Amendments Act of 1988" was, according to Lori Rogovin, a Washington lobbyist for the American Association for Counseling and Development, a "compromise" bill at best, sadly marking only a beginning step

to the many issues surrounding the AIDS epidemic (personal communication, October 25, 1988).

Resistance could also be observed in the search for new biotechnology to combat AIDS in the 1980s. Like funding, new drugs and vaccines were political issues. In the United States, the release of new drugs into the common marketplace falls under the auspices of the Food and Drug Administration (FDA). Under FDA regulations, three phases of drug testing occur. Phase I trials, of short duration and involving a small number of patients, are designed to determine the safe dose range of a new drug and how the body deals with it. Phase II trials aim at determining whether a new drug has therapeutic efficacy and usually involve several hundred volunteers. Tests at this phase are controlled using a double blind regimen in which neither doctors nor patients know who receives the experimental drug or the control. Phase III trials typically include thousands of volunteers at multiple research centers and help to further define how and when a drug is optimally safe and effective (American Foundation for AIDS Research, 1988). Not until the end of 1988 did the FDA decide to revise new drug approval procedures in an attempt to make new treatments available more quickly to people with AIDS. Until the FDA revisions went into effect, the average time for the approval of drugs was 8 years (Leary, 1988). This stands in stark contrast to other countries, most notably France, home to the Pasteur Institute, one of the world's most important centers for treatment research. The French eagerly tested all sorts of drugs on AIDS patients, cognizant that the alternative to treatment was death (Shilts, 1988). Pasteur doctors considered Americans barbarous for not aggressively pursuing every possible means of treatment and considered double blind studies cruel and inhumane in that they precluded the patient who received a placebo from any chance of survival (Shilts).

Resistance to AIDS was not merely restricted to the legislative branches of government and its affiliated agencies. The press, watchguard of the government, was admittedly lax in its coverage of AIDS.

In the early days of the epidemic the media shied away from AIDS. In 1982 the *Morbidity and Mortality Weekly Report* announcement about KS received a one-day infusion of press attention and garnered obligatory stories in the *New York Times* and the *Los Angeles Times*, carefully crafted so as not to offend or cause panic (Shilts, 1988). By contrast, the discovery of ex-

amide in Tylenol capsules, which occurred at the same time, prompted the *New York Times* to write a story on the scare every day for the entire month of October and produce 23 more pieces in the 2 months following (Shilts). In *And the Band Played On*, Shilts wrote that in 1982 "one could have lived in New York, or in most of the United States for that matter, and not even have been aware from the daily newspapers that an epidemic was happening, even while government doctors themselves were predicting that the scourge would wipe out the lives of tens of thousands" (p. 191).

Political factors also influenced how reporters covered the AIDS crisis. Altman (1986) suggested that for the most part, the media avoided AIDS because they viewed it largely as a gay story. Once the illness appeared among infants and those who had received blood transfusions, attitudes changed dramatically. From early 1983 on, AIDS became a continuing preoccupation of the media. However, by that time the media had firmly established the homosexual character of the disease and the discovery of other affected groups changed this perception little (Altman, 1986).

Shilts (1988) pointed out that reporting on AIDS clearly followed a pattern: the stories were carefully written not to cause fear and always ended on a note of optimism. Virtually every news story stressed that AIDS was not casually infectious and that it posed no threat to the general public. Absent from early media coverage were clearly presented discussions of the specific sexual practices that spread AIDS, most notably anal intercourse.

While the federal government and media struggled to come to grips with the AIDS crisis, those closest to the illness formed politically oriented grass-roots movements. This active resistance movement was seen in candle-lit marches across the country, in demonstrations and rallies, in the thousands and thousands of handmade panels of the eulogistic "Names" quilt that filled the Washington mall in October 1987. Organizations like MAP, Mothers of AIDS Patients, called attention to the impact of AIDS on families during the 1988 presidential campaign while ACT-UP, the AIDS Coalition to Unleash Power, advocated civil disobedience as a way of channeling their growing anger over what they viewed as a maddeningly slow research effort.

Implications for counseling. Counselors need to be aware that their clients with AIDS or at risk for AIDS live in what has been a politically hostile environment. PWAs' lack of political power

is often internalized, resulting in feelings of helplessness, hopelessness, and despair. Counselors need to empower their clients, combating resistance on the political and psychological fronts. Counselors need to examine their role in the political apathy toward AIDS and the impact their own political resistance may have on the lives of their clients.

An Emergent Trend in Society: Dealing With the Disenfranchised

Society has often struggled with ways of dealing with the disenfranchised, the segment of people who, for whatever reason, are discarded by the majority. AIDS confronted society with an inordinate challenge—attending to stigmatized people with life threatening illnesses. In the 1980s two major trends in "coping" with the societal aspects of AIDS emerged, prejudice and caring.

The early days of the AIDS epidemic provided the raw materials for the fear and prejudice that have become so deeply ingrained in the crisis. Characterizing risk groups by the four Hs—homosexuals, heroin addicts, hemophiliacs, and Haitians—instead of by riskiness of behaviors, further stigmatized already stigmatized groups.

Gay men suffered perhaps the most blatant forms of prejudice and hatred. Graffiti bearing messages like "AIDS—Americans' Ideal Death Sentence" became common (Altman, 1986). Columns in newspapers bore headlines like "AIDS Disease: It's Nature Striking Back," and argued that gays should be banned from such activities as food handling and child care (Altman). Stulberg and Smith (1988) reported that almost one fifth of the gay men they sampled had experienced discrimination specifically as a result of AIDS. A survey done in October, 1988, by the *New York Times* and *CBS News* reported that whereas most respondents expressed sympathy toward people with AIDS in general, they expressed little or no sympathy toward people who get AIDS from homosexual activity (Kagay, 1988).

Prejudice against gays was not limited to the general populace but occurred in the medical profession as well. An editorial by Dr. James Fletcher appeared in the *Southern Medical Journal*, the official publication of the Southern Medical Association, claiming that "homosexuality is not 'alternative' behavior at all, but as the ancient wisdom of the Bible states, most

certainly pathologic" (in Altman, 1986). Baumgartner (1985) reported on health care professionals who, because of their discomfort in dealing with AIDS patients, enforce excessive infection control practices that leave their patients in isolation.

Haitians, too, suffered from incredible intolerance as a result of being included as a risk category. Whereas the media and researchers rushed to investigate every aspect of gay male life and how it had been affected by the epidemic, Haitians attracted far less attention (Altman, 1986). The classification of Haitians stirred controversy centering on whether it was correct to regard a nation as a whole as being at risk for AIDS. Dissenters claimed that a large percentage of Haitians were either homosexual or drug users and that the CDC ignored this due to a lack of interviewers skilled in Creole and aware of Haitian taboos (Altman). Although Haitians were eventually removed from the list of high-risk groups by the CDC, this extrication did little to alter the everyday discrimination AIDS presented for Haitians in North America (Altman).

Hemophiliacs risked exposure to the HIV virus through their use of Factor VIII, a product used to help clotting that is made from the plasma of large numbers of donors. Hemophiliacs became more inclined to hide their illness after the onset of the AIDS crisis, fearing exposure to the same sorts of prejudice other risk groups experienced (Altman, 1986).

Prejudice also emerged in the form of racism. Both within and outside the gay community, AIDS has been seen as largely a White disease resulting in a lack of comprehensive education and prevention programs as well as medical, psychological, and other support services directed specifically at people of color. This occurred despite the high incidence of AIDS among Black and Hispanic men (Altman, 1986).

Not all of society responded to AIDS with fear, loathing, and hatred. One of the most remarkable byproducts of the HIV epidemic was the development of community-based organizations dedicated to serving the needs of people with AIDS (Emeberg, 1988). These organizations, many of them nonprofit and locally organized, provided thousands of volunteer hours of assistance and comfort to people with AIDS and their loved ones. They developed and operated AIDS telephone crisis lines, provided advocacy, and in many cases conceived, printed, and distributed the first prevention and education material.

A special community was created by people who themselves were HIV-infected. The "People With AIDS" movement grew

out of shared anger. Sick of being called AIDS victims, with heavy connotations of passivity and helplessness, these people fought actively to regain their health (Shilts, 1988). Tired of being called patients even when they were not in the hospital (Shilts), they mobilized, using insights gained from their personal struggles with AIDS, to contribute to the larger battle.

Implications for counseling. In order to work effectively with people with AIDS or at risk for AIDS, counselors will need to examine their own prejudices with respect to minority populations. How a counselor feels about gays, Blacks, Hispanics, intravenous drug users, and even hemophiliacs will influence his or her ability to understand and empathize with the client. Counselors working with PWAs or people at risk for AIDS will often have to work through the hurt and anger a client experiences as a result of societal hatred. Counselors will have to assure and reassure their clients that they will treat them differently than other people they may have encountered, that they will approach them with caring as opposed to condemnation.

An Emergent Trend in Education: "Just Say No"

Education plays the central role in the prevention of the AIDS crisis. Gallo and Montagnier (1988) wrote that, "even without a vaccine or a cure, what is already known could bring the epidemic under control" and that "there is a need for education about HIV infection—in clear, explicit language and as early as possible" (p. 48). Educational efforts of the 80s struggled with complex confounding issues of dogma and morality, and found it difficult, for the most part, to provide the cogent information that experts on AIDS called for. Instead, educational efforts in the 80s appropriated the catch phrase of the nation's drug prevention program and urged the American public to "just say no" to AIDS. How to say no, or what exactly to say no to, were disguised, disinfected, or altogether disregarded in educational programs and pamphlets.

Political forces may have influenced the minimalist approach to AIDS prevention. White House conservatives were convinced that AIDS education programs were cleverly designed covers to promote sodomy and sexual promiscuity (Shilts, 1988). An official Department of Education handbook, approved by the White House, urged teachers to stress "appro-

priate moral and social conduct" as the first line of defense against AIDS (Shilts). Many congressional efforts to forge bipartisan consensus on issues of research and education tended to fall apart on politically touchy issues like nondiscrimination hampered by ultraconservative Senator Jesse Helms's amendments decrying homosexuality.

A bright light in the field of education was embodied by Surgeon General C. Everett Koop. Koop, himself an ultraconservative fundamentalist, spent much of 1986 interviewing scientists, health officials, and gay community leaders. Out of those interviews he prepared the "Surgeon General's Report on Acquired Immune Deficiency Syndrome" and had tens of thousands of copies of the text printed and mailed to homes across the country. The report addressed, for one of the first times, the problem of AIDS in purely public health terms. Koop (1986) wrote that education should start at the earliest grade possible for children. He bluntly advocated widespread use of condoms and maintained that compulsory identification of virus carriers would be useless in fighting the disease.

Despite the surgeon general's report, by early 1987, the United States was still the only major industrialized nation that had not launched a coordinated education campaign against AIDS (Shilts, 1988). In contrast, European countries launched campaigns using billboards, newspaper advertisements, and television commercials urging people not to "die of ignorance" (Shilts).

Early educational efforts evolved within the gay community. Watson (1984) noted that gay men have been bombarded with more medical information than one person would normally receive in a lifetime. From the onset, the gay community in particular was challenged by the problem of developing preventive education about the need for moderating high-risk behaviors and adopting "safer sex" techniques (Martin & Vance, 1984).

Even with the best of intentions, the "just say no" approach to education was criticized as ineffective and misleading. Shernoff (1988) observed that highly visible and well-placed professionals provided unrealistic and unfounded advice regarding AIDS prevention. He offers former president of the American Association for Sex Educators, Counselors and Therapists, Teresa Crenshaw's statement that "the only absolutely safe sex is celibacy or masturbation" as an example. Shernoff maintained that although the statement is true in the abstract, it is unrealistic and irresponsible to expect people to either stop having sex or simply masturbate. Cochros (1988) corroborated this point, of-

fering an astute quip by I. Reiss, professor at the University of Minnesota, who suggested that "vows of celibacy have a far higher breakage rate than condoms" (p. 255). Palacios-Jimenez and Shernoff (1988) found that when people ceased to abstain from sex after periods of "unwanted" celibacy, they were likely to engage in high-risk behavior. The "just say no" to sex campaign's greatest flaw lay in its inability to take into consideration the psychological functions sexual activities serve in many human beings. Gochros wrote that "by emphasizing the dangers of sex and ignoring the fact that most responsible sexual acts by most responsible people do not lead to pregnancy, disease, or death, the healthy, joyful naturalness of sexuality is obscured" (p. 256).

Educators often admonished entering into and maintaining a monogamous sexual relationship as the alternative to abstinence. This too is mistaken information; unless testing has established that both partners have not been exposed to HIV, there is little to ensure that a monogamous relationship is virus-free (Gochros, 1988). Advising clients to reduce their number of sex partners is, in and of itself, not helpful or even accurate (Shernoff, 1988). An individual who is the receptive partner in anal or vaginal intercourse with one seropositive person is at higher risk for becoming infected than a person who is involved in mutual masturbation with several different partners, regardless of their antibody status (Shernoff). Gochros critiques other educational efforts to reduce the risk of AIDS in that they often treat sexual practices conforming to "safer sex" guidelines as second best.

Although in some of the most severely affected communities, sustained and intensive educational efforts were rewarded by striking changes in behavior, the gap between knowledge and personal action remained wide (Fineberg, 1988). In a national poll conducted in August 1987, more than 90% of Americans knew they could contract AIDS from having sex or sharing needles with an infected person. When asked about the possibility of contracting AIDS themselves, 90% of all respondents viewed their own risk as low or nonexistent (Fineberg). Fineberg wrote that "if the effectiveness of education is to be measured by behavioral change, success will not come easy" (p. 130). Gochros (1988) maintained that educators must deal with a cultural history in which condoms were seen as a symbol of immoral, clandestine, casual, and dirty sex. Furthermore, educators must assert that sexual desire, planned sexual

encounters, sexual talk between actual or potential sexual partners, and condoms are good common sense.

Implications for counseling. Counseling is a form of educating, giving people new ways of seeing their world and new tools for interacting with it. Like a teacher who carefully reviews the curriculum of a class he or she will teach, counselors must examine the information on AIDS they will provide to their clients. Counselors must provide clients with clear, concise, and accurate information about AIDS and how it can be prevented.

An Emergent Trend in Counseling: Empowerment

If a single goal unifies all counselor orientations and approaches to treatment in the AIDS crisis, it is the goal of empowering those affected by AIDS. Empowerment demands that counselors and other human development specialists offer people the hope and tools needed to live a meaningful life in the face of a crisis.

Psychological effects of AIDS, both on the individual and on the collective psyche were slowly recognized in the 80s. Morin, Charles, and Malyon (1984) and Morin and Batchelor (1984) reported that whereas medical needs of people diagnosed with AIDS were being met, psychological needs were not. This is calamitous because AIDS patients are at high risk for psychological problems that are often underdiagnosed and undertreated (Perry & Tross, 1984).

Haney (1988), a social worker with AIDS, viewed many of the potential psychosocial consequences of AIDS as disconnections. AIDS disconnects people from the past, present, and future, from loved ones, from their ways of defining themselves such as job activities, capabilities, skills, and physical appearance, and, perhaps most importantly, from a sense of power and control over their life, hopes, dreams, and aspirations.

Goulden, Todd, and Hay (1984) suggested several steps in empowering clients with AIDS that center on the relief of depression. These steps included adopting stress-reducing activities, participating in support groups, channeling anger constructively, improving the quality of relationships, and avoiding the abuse of drugs and alcohol.

Counselors helping people with AIDS found they had to assist them to focus on learning to live with the illness. Haney (1988) offered six ways of providing empowerment to persons

with AIDS. First, mental health professionals could help their clients focus on the positive, less fatalistic aspects of having AIDS. This is not to suggest denial but rather a reframing of the situation emphasizing how to make the most of an otherwise negative situation. Second, there is a healing power in hope and caring that the mental health worker must provide when others in the client's life are unable to supply this need. Third, mental health professionals could help people with AIDS reconnect with a support system. Fourth, mental health professionals could teach people with AIDS procedures to gain control of their illness and their lives. This could be accomplished in many different ways, from teaching creative visualization or guided meditation to offering anxiety and stress-reduction techniques. Fifth, mental health workers could help people with AIDS get rid of their victim mind-set. Finally, counselors can become advocates for the needs and rights of people with AIDS, standing by the belief in all people's worth and dignity.

Morin and Batchelor (1984) saw issues of loss and bereavement as important topics that must be addressed by people with AIDS, their lovers, and significant others. Baumgartner (1985) suggested that the healthy may need help in coping with "survivor's guilt," a constant wondering of why they survived accompanied by a fear of reinvesting themselves emotionally and sexually in new relationships. Lopez and Getzel (1984) recognized the existence of community mourning, also known as bereavement overload. Dr. James W. Dilly, executive director of the AIDS Health Project in San Francisco expressed fear that his city would be ill prepared for the "overload of grief" it would face as the AIDS death rate doubled, to six people a day by 1993 (Zonana & Moran, 1988).

Implications for counseling. Counselors working with people with AIDS and people at risk for AIDS will need to find ways to integrate into their practice techniques for empowering clients. Counselors will need to be prepared to confront grief reactions of immense intensity in their clients and in themselves. More than ever, counselors will need to find colleagues who can support and encourage their work.

AIDS in the Nineties: What Can Counselors Expect?

It is apparent from looking at the first decade of the AIDS crisis that the future will undoubtedly entail greater involve-

ment on the part of counselors, educators, psychologists, social workers, nurses, and the world at large. Mann, Chin, Piot, and Quinn (1988) stated that although the AIDS pandemic is still in its early stages, it is apparent that AIDS is an unprecedented threat to global health. They see the global situation getting much worse before it can be brought under control.

Having examined the past, what projections can be made for the future of the AIDS crisis? Each day offers a change in the status of AIDS, whether that be in the realm of medicine, politics, social conditions, education, or counseling, making predicting the future a precarious task. Nonetheless, given the previously elaborated trends, it seems reasonable to suggest, at least tentatively, 10 areas for which counselors might prepare.

1. Counselors will see the number of AIDS cases continue to increase. Reports to the World Health Organization suggest that at least 5 million people worldwide are infected by the AIDS virus and that a million new cases of AIDS are likely by 1995 (Mann et al., 1988). Whether by working directly with people with AIDS, working with children whose parents have AIDS, or working with schools with HIV-infected students, counselors will inevitably find AIDS a part of their profession.

2. Counselors will face an increasing number of infected infants and children. Heyward and Curran (1988) indicated that children make up the fastest growing group of reported AIDS patients. In New York City in 1988, between 1% and 2% of all women giving birth were found to be infected with HIV (Emeberg, 1988). Most of these cases can be traced to intravenous drug use by the child's mother or her sexual partner. Counselors will have to develop new approaches to counseling these children in the coming decade.

3. Revisions will be needed in the nation's programs of providing health services. The AIDS epidemic will exacerbate the shortcomings in the system of paying for health care in the United States. In 1988, one in five AIDS patients had no insurance, 40% of AIDS patients were covered by Medicaid, which frequently paid less than the cost of care, and private insurers were often reluctant to cover the kinds of services most needed by people infected with HIV (Emeberg, 1988). Most private insurance is linked to employment, ensuring that at some point the prolonged illness of AIDS will result in the loss of insurance. Other major Western countries provide some sort of national health insurance, so that people struck with catastrophic illness do not find themselves scrambling to pay for basic care (Altman,

1986). Suggested ways of remedying the United States' problems in paying for health care include: state-based insurance risk pools or subsidies for uninsured patients, reliance on case managers to determine whether insurers should pay for services normally not covered, adjustments in the national standards of Medicaid eligibility and payment, simplification of the procedures for states to request flexibility in Medicaid coverage, further extension of insurance coverage for employees who lose their jobs, mandated employer health insurance, and broadened federal and state support of health insurance (Fineberg). If changes are not implemented and third-party reimbursement for mental health services is not available to people with HIV infections, low fee, community mental health clinics will be inundated with the burden of becoming the primary provider of treatment to people with AIDS.

4. Counselors will find increased attention placed on the plight of AIDS in Third World countries. In parts of Africa and the Caribbean, HIV infection is more prevalent than in the United States (Fineberg, 1988). Shilts (1988) reported a predominant feeling at the IV International AIDS Conference in Stockholm in 1988 that the true weight of the future AIDS epidemic would fall on the shoulders of health professionals in the Third World. Demographic projections suggest that the long-term impact of AIDS on Third World nations may be similar to that of a prolonged war (Fineberg). Gallo and Montagnier (1988) maintained that education alone will not stem the epidemic in some areas of the developing world and claimed that other measures will be necessary. Counselors will need to take a global perspective in their work with AIDS, networking with mental health professionals in Third World countries or offering to work in those countries themselves.

5. Counselors will be needed to minister to the inner city as it becomes plagued by the AIDS epidemic. For people in the inner city, a diagnosis of AIDS compounds the social stigma and low self-esteem they already experience as a result of their socioeconomic class. Numerous critical issues exist for HIV-infected residents of the inner city that will need to be addressed by counselors in the 1990s. Many people with AIDS in the inner city are IV drug users and therefore face a more rapid disease course than do non-IV drug users with AIDS (Marmor, 1984). Counselors will need to address the generally negative attitude toward IV drug users that has resulted in little professional support and few existing community resources (Honey, 1988).

Counselors will also have to contend with the lack of housing for people with AIDS in the inner city (Honey). Counselors will have to revise AIDS prevention education, which has frequently failed to take into account the cultural differences in sexual relationships among ethnic minority couples living in the inner city (Shernoff, 1988). Counselors will need to plan for long-term care of children if a parent with AIDS dies or is unable to care for the child. This task will be greatly compounded if the child is also infected, making placement in foster or adoptive homes extremely difficult (Honey).

6. Counselors will see AIDS become a significant legal issue. Given the current social and political climate of the nation, an increasing number of legal battles will be a part of the AIDS crisis of the 90s. Issues of quarantine are likely. The breach of confidentiality, already an issue in the late 80s (Gray & Harding, 1988; Kain, 1988), will be the basis for new legal rulings and legislation affecting the practice of psychotherapy and counseling.

7. Counselors will wait for scientists to develop new drugs and vaccines against the HIV. These scientists will, however, have to overcome shortfalls in funding and difficulties inherent in the HIV. Thomas (1988) wrote that a new class of antiviral drugs is needed, one capable of killing viruses inside the cells they invade without killing the cells themselves, but that the development of such pharmacological wonders is most difficult and unpredictable. Mathews and Bolognesi (1988) reported that the task of developing a vaccine is arduous in the face of one of the most intractable viral diseases in medical history, and pointed out four factors that make finding a vaccine for AIDS particularly difficult. First, ethical concerns abound because the only way to be sure a vaccine has warded off disease is to inject the vaccine recipient with HIV and observe the consequences. Second, clinicians expect to be confronted with a shortage of trial volunteers because healthy people may be reluctant to try a vaccine that has no demonstrated efficacy and because there simply may not be enough people in high-risk categories to provide statistically significant results. Third, recruitment problems will only worsen as more vaccines are developed, each requiring thousands of people for testing. Finally, uncertainty surrounding the risks and liability of vaccine-related injuries and compensation for them could ultimately hinder vaccine development. Given these difficulties, "avoiding" AIDS by placing all hope on a cure will not be a realistic option for counselors

or their clients; instead both will be forced to confront the excruciatingly painful issues that loom in the days ahead.

8. New counselors and other health professionals will be needed to take the place of health professionals exhausted and depleted by their work with the epidemic. Emeberg (1988) reported that fewer physicians today are choosing to pursue careers in internal medicine, suggesting that AIDS may be part of the reason. Simmons-Alling (1984) characterized four ways in which mental health professionals are affected by working with HIV-infected clients: A-anxiety, I-isolation, D-drain, and S-stress, any of which can lead to professional burnout. Dr. Joel Weisman, who co-reported the first cases of AIDS in Los Angeles in June 1980, feels that there is an "avoidance phenomenon" among health professionals and that "while in an ideal world, every physician should treat the patient with AIDS, in the real world, that's just not going to happen" (Simross, 1988). The counseling profession will need to counter its own trend toward avoidance with involvement. Counselors will need to find ways to work with people afraid of AIDS, at risk for AIDS, or ill with AIDS, so as to minimize their own emotional burnout.

9. Hospice will become more recognized as a preferred way of caring for people with AIDS. The use of an interdisciplinary team approach to working with people dying of AIDS greatly benefits both the person with AIDS and the team members. Counselors will find themselves included in these teams along with physicians, nurses, pastoral care persons, and trained volunteers. Additionally, because hospice care is often offered in the patient's home or in special supportive care environments, clients will no longer be able to come to counselors' offices. Counselors will have to go to their clients.

10. Compassion will be greatly needed. In the face of the escalating tragedy of AIDS that affronts the world in the decade of the 1990s, it will be important for counselors and others to find the human side to the crisis. Compassion may, more than anything, be the crucial determinant of the future of the AIDS epidemic.

Summary and Conclusion

Much can be written about the first decade of the AIDS crisis and certainly much more will be written. This chapter

examined five major areas affected by the major health crisis of the 80s and quite possibly that of the 90s. Medicine, politics, society, education, and counseling have all, in one way or another, been called upon to meet the challenge of AIDS. In the last 10 years many trends have appeared: new words, new political battles, new forms of old prejudice, new lessons to be learned, and a new class of clients needing help. Each of these trends has affected the field of counseling. The next 10 years will undoubtedly bring many more trends; 10 such future trends were mentioned in the course of this chapter. Crucial to the future of AIDS is how we, as counselors, respond to the calls for help we receive. In the face of whatever frustration, resentment, anxiety, or stress we may encounter, can we open our hearts and offer those suffering from the effects of AIDS our intelligence, our integrity, our selflessness and our compassion? I hope our answer to this question is affirmative. The importance of our answer is captured by His Holiness Tenzin Gayso, the Fourteenth Dali Lama when he says, "Out of my experience, I tell my friends wherever I go about the importance of love and compassion. Deep down we must have real affection for each other, a clear realization or recognition of our shared human status."

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Chapter 2

A RESEARCH UPDATE FOR COUNSELORS

Joseph R. Gaydish and Maria Ekstrand

A child in your school district has been diagnosed with AIDS. The parents are distraught, one teacher has refused to have the child in class, parents of other children do not yet know, and the child understands only that he is scared and sick. When the principal phones to set a meeting, you mark the anxiety in her voice.

A physician refers a young woman with AIDS. Infected by her bisexual ex-husband, she was sick for months before the diagnosis was made. AIDS was unexpected in a heterosexual woman with no history of intravenous (IV) drug use. Ridden by fatigue and nausea, she is no longer able to work or adequately care for her two young children. After being in therapy for several months, she dies.

These are scenarios of AIDS in America. To those already initiated they represent scenarios of today, and for the uninitiated they are scenarios of tomorrow. Counselors have a pivotal and expanding role in responding to the AIDS epidemic. The goal of this chapter is to provide counselors with a survey of current and clinically focused HIV-related research. After a brief review of HIV epidemiology, our discussion is organized

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in terms of those at risk of infection, those who are seropositive but asymptomatic, and those who are diagnosed with AIDS or ARC. Our central theme is prevention, which continues to hold the greatest hope for slowing the spread of HIV and minimizing the associated human suffering and loss of life.

Current Epidemiology

It is now over 8 years since the initial and foreboding reports of pneumocystis carinii pneumonia (PCP) and Kaposi's sarcoma (KS) among homosexual men appeared (Centers for Disease Control, 1981a; CDC, 1981b). The World Health Organization (WHO) reported nearly 112,000 AIDS cases in 140 countries as of August 1988 (CDC, 1988a). Worldwide reporting is incomplete, however, due to inadequate health care and AIDS diagnostic facilities in some areas, and because some governments were slow to acknowledge the presence of AIDS in their country (Piot, Plummer, Mhalu, Lamboray, Chin, & Mann, 1988). Consequently, the WHO estimates 250,000 to 300,000 AIDS cases globally, and 5 to 10 million people infected with HIV (CDC, 1988a; 1988b).

In the United States specifically, the Centers for Disease Control reported a cumulative total of over 76,000 cases in October 1988 (CDC, 1988c). Most adult U.S. AIDS cases (88%) are among gay and bisexual men or IV drug users, 4% among non-IV drug using heterosexuals, and the remaining cases are related to hemophilia, blood transfusion, or are undetermined (CDC, 1988c). Because the case count increases substantially each week, future projections communicate more effectively the magnitude of the epidemic. By 1992, 365,000 U.S. AIDS patients will have been diagnosed, of whom 263,000 will have died. Currently, 1 to 1.5 million people in the United States are thought to be infected with HIV (CDC, 1988d). The magnitude of the epidemic now, coupled with its projected growth, necessitates that counselors be well informed about AIDS.

Persons at Risk

HIV is now well entrenched in the United States, and everyone is at some risk of infection. Individuals most in danger

of HIV infection, however, are at risk because they engage in behaviors that facilitate viral transmission, primarily unprotected anal and vaginal intercourse and IV drug use. Researchers often use the term "HIV spectrum disease" to reflect the growing awareness that the many manifestations of HIV infection are symptomatic of the same immunologic dysfunction. Specifically, the distinction between AIDS and ARC has come under fire because it applies different diagnoses where there is no difference in the underlying causal agent (HIV), or the underlying disease process. Although current knowledge about HIV spectrum disease is organized by risk groups, and although risk group generalizations are useful in planning and targeting interventions, risk of infection is determined by individual behavior.

It now seems that nearly all persons infected with HIV will eventually develop AIDS (Lui, Darrow, & Rutherford, 1988; Lemp et al., 1988), a disease that remains both incurable and fatal. Consequently, the central issue in working with persons at risk is the prevention of infection by changing risk-related behaviors. In the sections below we discuss a theoretical model of health behavior change, followed by recent HIV-related prevention literature organized by groups at risk.

The Health Belief Model of Risk Reduction

A modified version of the health belief model (HBM) provides a theoretical framework for studying risk behaviors, designing risk reduction interventions, and counseling individuals for behavior change. Based on the classic Health Belief Model (Becker, 1974), the modified version also incorporates self-efficacy theory (Bandura, 1986) and the importance of perceived peer and social norms. The role of self-efficacy in health behavior has gained increasing recognition, and this construct was recently incorporated into the classic HBM (Rosenstock, Strecher, & Becker, 1988).

The HBM assumes that beliefs are major determinants of behavior, and several types of beliefs are thought to influence preventive health action: (1) knowledge of the disease and of preventive behavior; (2) perceived susceptibility to a given disease and beliefs regarding the severity of the consequences; (3) the perceived benefits and costs of engaging in preventive behavior; (4) a cue to action that triggers preventive behavior,

such as the illness of a friend or reading about the disease; (5) peer and social norms, which may be perceived as supporting or discouraging preventive behavior; and (6) a sense of self-efficacy, or seeing oneself as capable of engaging in preventive behavior.

Effective HIV prevention strategies typically address multiple aspects of the health belief model, such as enhancing self-efficacy or intervening to change community norms, in addition to increasing knowledge. We will return to the HBM at the end of this chapter to further discuss its application to the problems of changing risk behavior.

Risk Reduction Among Gay Men

Gay men in San Francisco have made significant and lasting risk behavior changes in response to AIDS. Several reports document reductions in the number of sexual partners and frequency of unprotected insertive and receptive anal intercourse, both firmly established high-risk behaviors for the transmission of HIV (Friedland & Klein, 1987).

The San Francisco City Clinic Cohort Study was initiated in 1978 to examine hepatitis B among men seeking treatment in a sexually transmitted disease (STD) clinic. A subsample (n = 125) of the original cohort was followed longitudinally to better understand the effects of HIV infection. Drastic behavior changes were reported in this sample by 1985, with 90% of participants reducing the number of partners from a median of 16 to a median 1 (Doll, Darrow, O'Malley, Bodecker, & Jaffee, 1987).

A longitudinal study of single men in the area of San Francisco hardest hit by the AIDS epidemic (San Francisco Men's Health Study) helped identify sexual behaviors associated with increased risk of infection and demonstrated significant reductions in the practice of these behaviors (Winkelstein et al., 1987a). In contrast to many types of behavior change, the reported reductions in sexual risk behavior are remarkably stable. Fewer than 6% of the gay and bisexual participants reported any recidivism following initial risk reduction (Ekstrand & Coates, 1988). Changes of this magnitude and stability are unprecedented in health behaviors (Coates, Stall, & Hoff, 1988), and laboratory data in this sample bear out self-reported behavior

change; the incidence of new infection is less than 1% per year (Winkelstein et al., 1987b).

Behavior change among gay and bisexual men is not limited to San Francisco. Martin (1987) studied 715 gay men in New York between 1981 and 1985. In this cohort 40% reported some change toward safer sexual practices, including a 72% reduction in number of partners. Similarly, the percent of participants in monogamous relationships increased from 8% to 14% during the study period. Other studies suggest that behavior change has occurred in gay communities outside of these AIDS epicenters, although the magnitude of change reported is usually less dramatic.

Predictors of risk reduction include being older, agreeing with health guidelines, and having a sense of personal efficacy. In contrast, the use of alcohol and drugs, denial, and the belief that one has been exposed to HIV but successfully "fought it off" have been associated with high-risk behaviors (Ekstrand & Coates, 1988; Stall, McKusick, Wiley, Coates, & Ostrow, 1986). Gay men at higher risk of infection may also be less open about their homosexuality, less likely to be members of gay organizations, have less satisfying social networks, and experience an absence of supportive norms compared with low-risk gay men (Joseph, Montgomery, Kessler, Ostrow, & Wortman, 1988).

Several authors have discussed the "San Francisco Model" in explaining risk reduction among gay men in this city (Coates & Greenblatt, in press; Catania, Coates, Kegeles, Ekstrand, Gavdish, & Bye, 1988). Prevention efforts in San Francisco have relied heavily on community-based approaches and volunteer organizations to change social norms related to sexual practices, and to encourage safe sex as an acceptable alternative to high-risk practices. One well-known community-based risk reduction program in San Francisco is STOP AIDS (Puckett & Bye, 1987), which uses small group formats to encourage risk reduction among gay men. Important components of this program include opportunities for participants to clarify thoughts and feelings about AIDS and its impact on the gay community, learn how others have adapted to the epidemic, share feelings about safe and unsafe sex, and express views about AIDS prevention needs that are then relayed to community leaders and organizations.

The results of the STOP AIDS program indicate that participants have a greater sense of personal responsibility for end-

ing the AIDS epidemic, that there is considerable support for the practice of safer sex in the gay and bisexual community, and that most participants can make a commitment to practice safe sex.

These findings have implications for counselors' prevention efforts. It is essential to target younger gay men, and particularly those not yet integrated into gay networks and organizations. These campaigns may be more successful if, in addition to health education, they assist participants in building social support, include social skills training components, and discourage having sex under the influence of alcohol and other drugs.

Risk Reduction Among Substance Abusers

Substance abuse is a linchpin in the continuing HIV epidemic. IV drug users represent 19% of U.S. AIDS cases reported through October 1988, with an additional 7% reported among gay men who also use IV drugs. Moreover, the proportion of AIDS cases each year having IV drug use as the only risk factor increased from 16% in 1987 to 23% in 1988 (CDC, 1988c). The spread of infection among IV users can be explosive, and HIV seroprevalence in some IV drug user samples is over 50% (Des Jarlais & Friedman, 1987).

Risk is not limited to needle users themselves, as 60% of heterosexually transmitted AIDS cases and over half of pediatric cases are among heterosexual partners and children of IV users (see Des Jarlais, Friedman, Casriel, & Kott, 1987). The secondary spread of HIV to sexual partners and children prompted one author to identify IV drug use as "the real heterosexual epidemic" (Moss, 1987, p. 389). The secondary spread of HIV related to IV drug use is also a Black and Hispanic epidemic. Of all heterosexual AIDS cases associated with IV drug use in the United States, 80% occurred in these two ethnic groups (Selik, Castro, & Pappaioanou, 1988).

The abuse of substances through non-IV routes is also associated with HIV infection. Substance abusing individuals may trade sex for drugs, use stimulant drugs to enhance sexual desire, or use hypnotics to decrease sexual inhibition (Clark & Washburn, 1988). Sexual activity occurring under drug influence is less likely to be safe sex (Stall et al., 1986), and the level of alcohol consumption is positively associated with high-risk

sexual behavior in heterosexual as well as gay and bisexual men in San Francisco (Guydish, Coates, & Ekstrand, 1988; Ekstrand & Coates, 1988). The use of crack cocaine in particular, now endemic among youth in some urban centers, may significantly increase risk of HIV infection. In one ethnographic study crack users reported higher numbers of sexual partners, more frequent infection with other STDs, and infrequent condom use, despite adequate knowledge about HIV transmission (Bowser, 1988). Finally, some drugs have immunosuppressive effects (Hubbard, Marsden, Cavanaugh, Rachal, & Ginzburg, 1988), and may facilitate infection or negatively affect the course of illness.

Successful prevention in segments of urban gay populations has come mainly from grass-roots efforts wherein specific gay communities mobilized political, financial, and educational resources necessary to stem the spread of the virus. Substance abusing populations, by contrast, typically lack the networks and resources to mobilize equivalent grass-roots efforts. Consequently, prevention among substance abusers is largely an effort of health care providers, public health professionals, and recovering addicts. Substance abuse treatment programs, because of their familiarity and acceptance by drug users, are likely centers for AIDS prevention. Sustained HIV prevention efforts conducted in drug treatment programs may reach beyond clients themselves to partners and families of users in treatment, and may have a secondary or ripple effect among users not in treatment (Bixler, Palacios-Jimenez, & Springer, 1987).

Although the discontinuation of drug use is the most desirable goal, effective prevention must include other strategies. Sorensen, Gibson, Heitzmann, Dumontet, & Acampora (1988) presented a conceptual framework for HIV prevention among substance abusers that includes four levels of individual protection. The strongest defense, and the one providing the best insurance against infection for IV drug users, is to stop drug use. A second but weaker defense is to stop using drugs through the intravenous route. The third level, for those who continue IV drug use, is to avoid sharing needles. For those who continue to share needles, the last defense is disinfecting needles with bleach prior to each injection.

Practitioners and researchers are deploying innovative prevention strategies consistent with these levels of defense, and are using multiple points of entry into the substance abusing

community. At one end of the spectrum, treatment programs are training clients in risk reduction practices (Sorensen et al., 1988), and conducting clinic-based outreach to IV drug users and their sexual partners (Gibson, Wermuth, Lovelle-Drache, Ergas, & Sorensen, 1988; Wermuth, Ham, & Gibson, 1988). At the opposite end of the spectrum, street outreach workers are delivering information and strategies to active addicts who may not want treatment at this time (Watters, 1987).

Risk Reduction Among Adolescents

Adolescents have a high prevalence of many behaviors related to HIV acquisition and transmission. A large proportion (50%–70%) of adolescents are sexually active, with a marked increase from 1971–1979 among 15–19-year-olds (Zelnik & Kantner, 1980; Harris, 1981). In addition, adolescents report very little condom use. Kegeles, Adler, and Irwin (1988) surveyed 325 sexually active teenagers over a 1-year period and found that although adolescents perceived condom use as preventing STDs and placed a high value on prevention, consistent condom use remained poor at the 1-year follow up (only 2% of women and 8% of men reported always using condoms).

That more adolescents are sexually active but few use condoms is supported by increasing rates of STDs in this age group. Approximately 50% of all STD cases occur in individuals under 25 years of age, and rates decrease exponentially with increasing age (NIAID, 1986; Bell & Holmes, 1984). Strunin and Hingson (1987) surveyed Massachusetts adolescents and found that of the 70% who were sexually active, only 15% had changed their behavior to reduce AIDS risk. Of those, only 20% used effective methods. Consequently, only 2% of adolescents in this sample engaged in effective HIV-preventive behaviors.

The latency between HIV infection and symptom development is so long that many of those infected as adolescents will not get sick until the early 20s, at the age where 20% of AIDS cases presently occur. Consistent with their level of cognitive development, many adolescents have a sense of immortality (Elkind, 1967), and are less likely to feel susceptible to HIV infection. Accordingly, many teenagers may find it difficult to engage in HIV-related preventive behaviors. Moreover, basic knowledge of AIDS and preventive behaviors among adolescents is highly variable and riddled with misperceptions

(DiClemente, Zorn, & Temoshok, 1986). For example, most students in this study knew that gay men are at increased risk of acquiring AIDS, but also believed lesbian women to be at high risk. Of all teenagers, minority adolescents seem to have the highest risk of infection. Fullilove and Fullilove (1987) found that minority adolescents initiate sexual activity earlier, report a more erratic use of contraceptive practices, have a greater likelihood of contracting STDs and becoming pregnant, delay treatment longer, and have less sexual education knowledge than White adolescents.

In summary, many sexually active adolescents currently seem to lack the knowledge, health beliefs, and probably also the skills needed for risk reduction. In order to be effective, prevention campaigns targeting this age group need to take the unique characteristics of adolescents into account.

Risk Reduction in the General Population

AIDS is a sexually transmitted disease. Data from partner studies, where sexual transmission from infected individuals to their heterosexual partners is studied, clearly demonstrate bidirectional transmission. In studies evaluating male to female transmission the proportion of infected partners ranges from 9% to 60%, and for female to male transmission it ranges from 0% to 100% (Padian, 1987). Those studies reporting the highest percentages included index partners from Haiti and Africa where, unlike in the United States, heterosexual transmission is a primary vector for the spread of HIV.

Several population-based studies indicate differences in the prevalence of HIV infection. Among blood donors, a population where seropositive individuals usually self-select out, about 1 in 5,000 tests positive (CDC, 1987). Among applicants for military service the prevalence is about 1 in 700 (Burke et al. 1987). Among patients admitted to six sentinel hospitals, inmates in the Federal Bureau of Prisons, and Job Corps entrants the prevalence is about 1 in 300 (CDC, 1988d).

Not all of those infected are in traditional "high-risk groups." The CDC currently estimates that 80,000 to 160,000 non-IV drug using heterosexuals are infected in the United States (CDC, 1988e). Moreover, as the pool of infected heterosexuals increases, the incidence of heterosexual infection is also likely to increase. Factors potentially associated with heterosexual infec-

tion risk include number of sexual partners (CDC, 1988f), drug use (Goldsmith, 1988), other sexually transmitted diseases (Simonsen et al., 1988), and heterosexual anal intercourse (Bolling & Voeller, 1987).

The heterosexual spread of AIDS is not expected to reach widespread and epidemic proportions (CDC, 1988d). Instead, heterosexual AIDS will probably develop in a pattern more similar to that of other STDs, where pockets of individuals who continue to engage in high-risk behaviors will become infected (Padian, 1987). From a public health viewpoint, however, any spread of a fatal but preventable disease is unacceptable.

Regarding heterosexual prevention, Hearst and Hulley (1988) suggested that knowledge of one's sexual partner prior to engaging in unprotected intercourse constitutes the most important precaution. This strategy assumes a rational, cautious, and time-consuming process of selecting sexual partners, a process not always practiced. It also implies, wrongly, that one can avoid infection by identifying safe partners rather than by practicing safe behaviors. Haverkos and Edelman (1988) advocated more conservative prevention strategies that include making all sexually active individuals aware of HIV infection risk, and reducing the number of sexual partners. Furthermore, during any sexual activity with **possibly** infected persons, contact with semen, vaginal secretions, and other fluids that may contain HIV should be avoided (Haverkos & Edelman). The emphasis here is on the practice of safe sexual behaviors, and the implication is that nearly all partners are "possibly" infected. Specifically, sexually active adults who are not involved in a long-standing monogamous relationship, or in a monogamous relationship where both partners have tested seronegative, are possibly infected.

Asymptomatic Seropositives

The discovery of HIV in 1983 and the availability of antibody testing in 1985 brought a new and difficult question: "Should I be tested?" Initially, many physicians and mental health professionals counseled against testing because (1) treatment for asymptomatic seropositives was not available, and (2) the knowledge of a positive test result could create significant stress that may itself contribute to immunocompromise. How-

ever, with the continuing spread of the epidemic, the expansion of knowledge about HIV, and the development of prophylactic treatments, testing is now strongly advocated by some (Redfield & Burke, 1988).

The mean incubation period of HIV, from infection to diagnosis, is variously estimated at 5 years, 7.8 years, and most recently at 11 years (Lemp et al., 1988). Significant individual and public health benefits may be realized in this time period if a person is aware of his or her seropositive status. Individual advantages include the possibility of slowing disease progression by preventing reinfection and by preventive treatment and health maintenance. Public health advantages include the opportunity to slow the spread of HIV by preventing infection of others. The individual costs of testing, of living with the knowledge of HIV infection, are also great. Working with seropositive individuals is discussed in a later chapter. Our focus here is limited to the role of antibody testing in risk behavior change, and the psychological and emotional impact of a positive test result.

The Role of Antibody Testing

In November 1984, 69% of all gay men participating in the AIDS Behavioral Research Project (N = 560) were interested in being tested once an antibody test was developed (Coates, Morin, & McKusick, 1987). In a follow-up study, after antibody testing became available, only 6% of this cohort had been tested and an additional 9% planned to be tested. Reasons cited for not having been tested included ambiguity regarding the meaning of a positive test result, lack of treatments for HIV infection, and confidentiality. The AIDS Behavioral Research Project also examined the behavioral and psychological consequences of testing. Those who were antibody positive showed significantly greater reductions in high-risk behaviors than both the negative and untested subjects. Ten seropositives reported still engaging in high-risk behaviors. Of the 10, 8 believed they had been exposed to HIV but that their bodies had successfully fought off the virus. A common motivation for testing was to find out whether one was capable of transmitting the virus. The authors point out that this has implications for public education programs, which might profitably focus on the desire to protect others as well as oneself. Antibody testing also had mental health

consequences, with seropositive men reporting increased levels of stress and depression, as well as an increase in relationship problems following testing.

Fox, Odaka, Brookmeyer, and Polk (1987) studied 1,001 gay and bisexual men in the Washington/Baltimore area in 1984–86. In this study 67% of men chose to learn their serostatus, and all of these men showed a decline in high-risk activity over the 18-month follow-up. However, a positive test result led to greater behavior change than did a negative one.

In a similar study, 270 homosexual men were surveyed at a Boston community health center (McCusker, Stoddard, Mayer, Zapka, Morrison, & Saltzman, 1988). Seropositive men who were informed of their results reduced the frequency of unprotected insertive anal intercourse more than did seronegative men. These participants also reported psychological consequences of knowing that they were seropositive. Specifically, they reported both depression (91%) and anger (89%) much more frequently than did the seropositives who were unaware of their status (65% and 0%, respectively).

The above findings are remarkably consistent. Testing and counseling among gay men seems to produce behavior change, particularly for seropositive individuals. This risk reduction has a cost, however. Seropositive individuals report increased psychological distress upon discovering their antibody status. This finding underscores the importance of counseling, with appropriate referrals to more extensive mental health services when needed, in combination with anonymous HIV testing.

These studies also highlight the dramatic emotional impact of HIV spectrum disease, as even asymptomatic individuals experience psychological distress on receiving a positive HIV test result. As patients later develop physical symptoms and ultimately receive an AIDS diagnosis, distress is likely to be a prominent and consistent emotional feature of the disease. One study reported a higher suicide rate for people with AIDS than for the general population, and higher than that for patients with Huntington's disease or cancer (Marzuk et al., 1988). This study was later criticized on methodological grounds (Beltangady, 1988), and further research is needed to clarify the relationship of HIV spectrum disease to suicide. In working with HIV-affected patients, the counselor should evaluate suicide potential as when working with other depressed, chronically ill, crisis, or dying patients.

Persons With AIDS and ARC

Central issues in working with people with AIDS/ARC (PWAs) include efforts to slow disease progression, enhance quality of life, and prevent infection of others. Although there are multiple and significant psychosocial issues in working with PWAs (Dilley, Ochitill, Perl, & Volberding, 1985), our discussion is limited to the biopsychosocial model, the psychological impact of an AIDS or ARC diagnosis, and the role of co-factors.

Biologically, AIDS is an immunoregulatory disease characterized by progressive deterioration of immune responsiveness, leaving the host open to a horrifying array of opportunistic infections that eventually result in death. Psychologically, AIDS may be characterized as a terminal illness or as a chronic debilitating illness, with all of the associated trauma, grief, and loss. Because AIDS continues to affect previously stigmatized segments of our society (gay men, IV drug users, and minorities), and because it is a costly and frightening disease, issues of prejudice and discrimination are boldly prominent.

For reasons such as these, AIDS and ARC require a biopsychosocial perspective that considers interactions of biological, emotional, behavioral, and cultural factors (Solomon & Temoshok, 1987). Although there is little experimental evidence that the course of HIV spectrum disease is affected by psychosocial factors, the more general relationship between stress and immunosuppression is now well accepted (e.g., Solomon, 1985). With respect to AIDS, repeated immunologic mobilization in response to biologic or psychosocial insult may activate latent HIV (Solomon & Temoshok) or further weaken an already embattled immune system. Continued IV drug use among seropositive individuals, for example, is associated with the rate of decline of T4 cells (Des Jarlais, Friedman, Marmor et al., 1987). Consequently, it is vital in the treatment of PWAs to consider behavioral, psychological, and social support factors that may bolster or maintain immunocompetence.

One such factor is the stress associated with the diagnosis itself. In a number of studies AIDS and ARC patients were compared with patients having more socially acceptable illnesses, such as chronic renal failure or bone marrow transplants, and with healthy controls. A diagnosis of AIDS or ARC often creates unique psychological problems not encountered

by other terminally ill patients. AIDS and ARC patients reported increased levels of anger and tension in response to their diagnosis. Many showed high levels of anxiety, depression, confusion, and bewilderment, possibly related to the uncertainty surrounding this disease. These patients were also more likely to express fears of social abandonment and isolation than the non-HIV terminally ill patients. Furthermore, many patients reported feelings of guilt and self-blame, sometimes seeing their illness as a form of punishment. The authors attribute these findings to the fact that AIDS is primarily a disease of those already shut out by mainstream society, and the fears of the general population that AIDS might be casually transmitted (Donlon, Wolcott, Gottlieb, & Landsverk, 1985; Nichols, 1985; Holland & Tross, 1985).

Several co-factors also are thought to affect immunocompetence, either by enabling transmission of HIV or by altering disease progression. HIV infection may be facilitated by genital ulcers, including those resulting from STDs such as chlamydia and herpes simplex virus 2 (Greenblatt, Lukehart, & Plummer, 1988). Similarly, the use of oral contraceptives is associated with an increased likelihood of infection among women (Plummer et al., 1988). Though the mechanism underlying this relationship is not known, oral contraceptives may change the composition of cervical mucus in a way that facilitates infection. Other possible co-factors include the number of sexual partners, engaging in receptive anal intercourse, and the lack of circumcision.

The most consistent factor for disease progression is duration of HIV infection, so that the longer a person has been infected the greater the likelihood of having disease symptoms (Jason, Lui, Ragni, Darrow, & Hessol, 1988). This robust relationship has been found in separate studies of the same population, as well as in studies comparing different populations. There have been fewer behavioral co-factors identified for disease progression than for infection. Hessol et al. (1988) examined the association between demographic, behavioral, and medical variables and the likelihood of developing AIDS. Using a multivariate analysis and controlling for duration of infection, the use of certain drugs (such as hallucinogens) and infection with other STDs (such as gonnorhea) were both associated with progression to AIDS.

The importance of co-factors in HIV spectrum disease is a matter of some contention, and the available data do not conclusively establish these variables as true biologic co-factors.

However, these studies clearly suggest that PWAs should avoid repeated infection with HIV, avoid contracting STDs by using condoms and reducing the number of sexual partners, and reduce or eliminate intake of alcohol and illicit drugs.

Implications for Counselors

As the epidemic continues to grow, extending beyond current geographic and risk group boundaries, counselors will be increasingly called upon to meet the myriad psychosocial challenges of HIV spectrum disease. On the near horizon there is neither cure nor vaccine, and the current most effective means of slowing the epidemic is prevention. This means preventing noninfected persons from becoming infected, preventing infected persons from infecting others, and, for those who are asymptomatic, slowing disease progression by attending to physical and emotional health needs.

The implementation of preventive interventions, targeting specific groups defined by age, ethnicity, or type of risk behavior, may minimize HIV infection among those at risk. Early identification of positive serostatus, close medical monitoring, and preventive health care are indicated for asymptomatic seropositives. For persons with AIDS or ARC, life-style modifications, enhancement of social support, avoidance of co-factors, and amelioration of the many psychosocial stressors attendant to disease are likely to improve both quality and duration of life. For all persons with HIV spectrum disease, preventing the infection of others is a paramount public health concern.

In helping individuals make those behavioral changes responsive to effective HIV prevention, the modified health belief model points to the importance of assessing HIV-related beliefs. Because knowledge alone is not a good predictor of preventive behavior, simply educating clients is not likely to lead to behavior change. Rather, the counselor should assess client beliefs using the framework of the HBM. Do seronegative clients see themselves as susceptible to AIDS or HIV infection or do they see themselves as somehow immune? Do seropositive clients believe they are capable of infecting others, or do they believe that they have a "less infectious strain" of the virus? Do they perceive AIDS as fatal, or do they think a cure will soon be found?

These examples, drawn from the literature reviewed in this chapter, suggest the varied and sometimes problematic beliefs

individuals may hold regarding AIDS and HIV infection. The HBM suggests the importance of developing a good sense of a client's belief system in the course of counseling for behavior change. The beliefs a given client holds, as well as the theoretical model of the counselor, will then determine the specific techniques used to change those beliefs that interfere with preventive behaviors.

The effectiveness of counseling interventions will also be increased by evaluating client beliefs about preventive behaviors. If the perceived costs of using condoms, reducing the number of partners, or avoiding anal intercourse outweigh the perceived benefits, the treatment program may need to include components designed to reduce these costs. Alternately, the counselor could work to increase the perceived benefits of safe sex or safe drug use behavior. Cognitive techniques such as "eroticizing" safe sex, or skills training (e.g., effective needle cleaning or correct condom use) may affect the perceived costs and benefits of preventive practices.

Similarly, a low sense of personal efficacy will also interfere with risk behavior change. A client who feels unable to use condoms because of a lack of skills will need a different intervention from one who is concerned about communicating the need for condom use to his or her partner. In general, self-efficacy can be increased by giving clients simple tasks at which they are likely to succeed. The difficulty and complexity of tasks can be increased gradually until the person has a sense of mastery, and an ability to perform the desired preventive task. Research has shown the importance of perceiving one's peers as supportive of healthy behaviors in the initiation and maintenance of health behavior change. This may be most easily accomplished in a group format and through community-based interventions. However, individual clients can be taught how to obtain support from friends and how to recruit friends likely to be supportive of healthy behaviors. This component of the HBM, when included in an intervention program, can reinforce and maintain preventive behaviors outside of the therapy setting.

Finally, altering community norms regarding risk behavior, although difficult to achieve, may be particularly effective in enabling widespread risk reduction. The counselor's role often extends beyond the individual consulting room and into a variety of community settings such as schools, universities, and mental health and substance abuse treatment agencies. Within these communities, counselors can devise and implement broad-based HIV

prevention strategies that target specific groups, and that attend to the unique needs and problems of these groups. This is not a new role for counselors, who have long been involved in multiple aspects of health and mental health prevention activities in communities across the country. Instead, it requires counselors to become increasingly active in applying preexisting community and organizational skills to the problems of HIV prevention.

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